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## Establishing Registries for Kidney Health Advocacy

### Results of the SharE-RR survey

Hole, B.<sup>1</sup>, Evans, K.<sup>1</sup>, Pyart, R.<sup>1</sup>, Davids, R.<sup>2</sup>, González Bedat M.C.<sup>3</sup>, Jager, K.<sup>4</sup>, McDonald, S.<sup>5</sup>, Pisoni, R.<sup>6</sup>, Rosa Diez, G.<sup>3</sup>, Saran, R.<sup>6</sup> & Caskey, F.<sup>1</sup>.

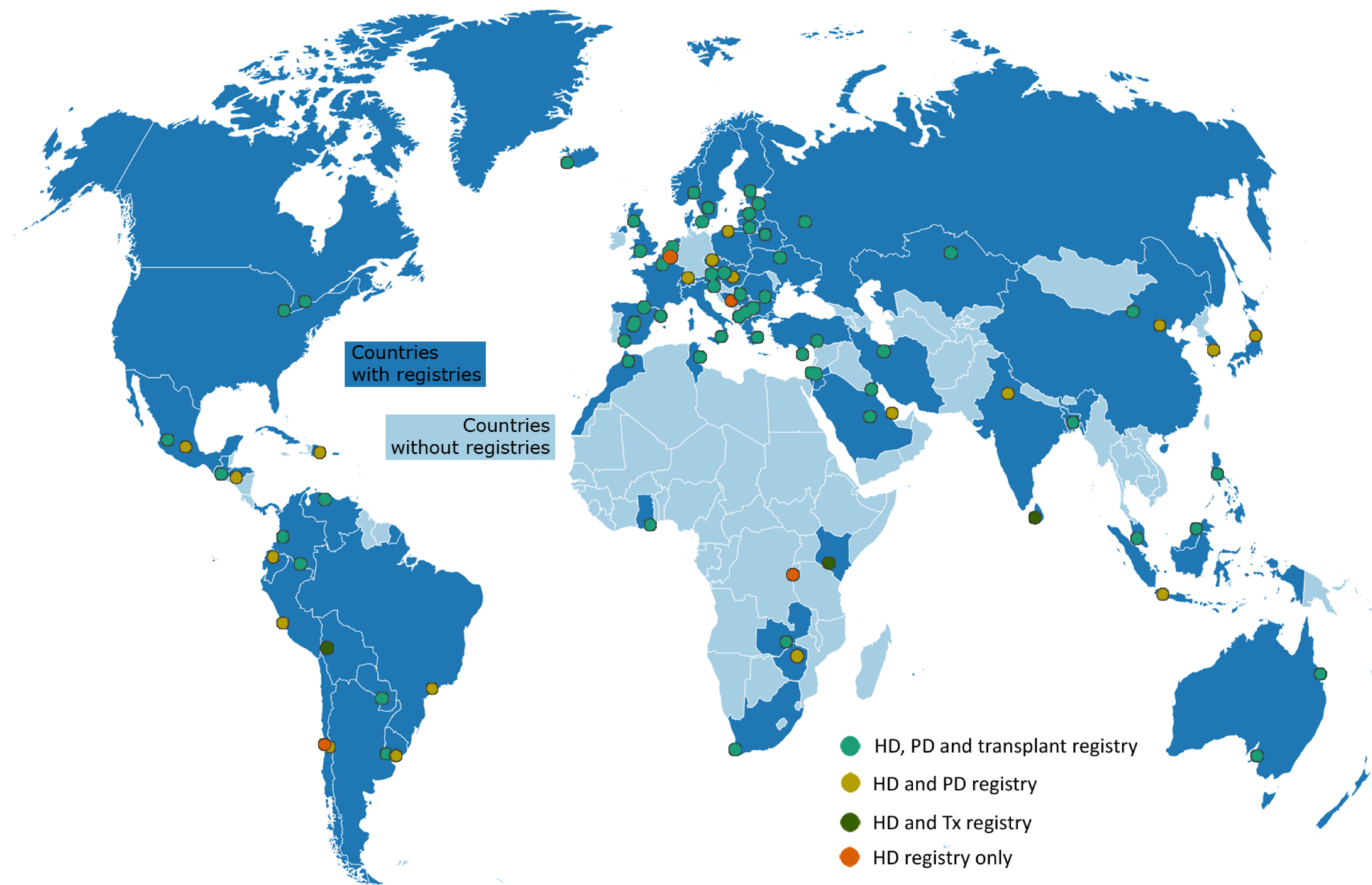
#### Introduction

The ISN advocates integrated worldwide renal care. Registries play a vital role defining disease burden, monitoring treatment & outcomes, but vary in coverage & structure. Expanding coverage is crucial for planning & monitoring effective preventative, renal-replacement & supportive care services. This study describes the scope & technical aspects of international renal registries.

In 2017 the ISN established 'Sharing Expertise to support the set-up of Renal Registries' (SharE-RR) to support countries developing a registry. SharE-RR started with a survey of world-wide renal registries.

#### Methods

Surveys were developed to collect geographical & modality coverage, models of data collection, technical, governance & funding information from national & international registries (SurveyMonkey, English language). Piloting & iterative development was undertaken with 6 registries in 3 continents. In 2018 the survey was emailed to 126 contacts provided by the African, Australian & New Zealand, ERA-EDTA, Latin American & United States (USRDS) renal registries. Surveys were administered in batches with reminders sent to non-responders. Respondents were asked to forward the survey to other registries covering renal replacement therapy in their country.



#### Results

85 registries in 78 countries responded

##### Modalities covered

99% of registries covered adults receiving haemodialysis, 92% peritoneal dialysis & 74% transplant. For children, these were 75%, 66% & 60% respectively

##### Economy

54% of responses were from high-income, 29% upper-middle, 15% lower-middle & 2% from low-income economies.

#### Data collection

52% of registries used web-forms to assimilate data, 36% paper-based, 28% email, 22% direct extraction from clinical systems, 16% via a secured data line & 5% using billing data. 46% used a mixture.

#### Funding

53% of registries declared funding direct from government (61% of high-income, 48% of upper middle-income, 38% of lower middle-income & 0% of low-income responders). Professional bodies/societies provided funding to 31% of registries. 8% of registries reported no funding.

#### Conclusion

International inequality exists in the ability to monitor access to renal care, its quality & outcomes. The most comprehensive registries are in higher-income nations & are more likely to receive government support. Scarce evidence of registry activity was reported by low-income countries. Collection of data relating to the background general population (denominator) is rare, precluding estimation of true disease burden. Paediatric coverage is less complete, though the survey may not have reached all registries. The SharE-RR project aims to make progress in these vital areas.

#### On behalf of the SharE-RR Project:

<sup>1</sup>UK Renal Registry; <sup>2</sup>African Renal Registry and South African Renal Registry; <sup>3</sup>Latin American Dialysis and Renal Transplantation Registry; <sup>4</sup>European Renal Association/European Dialysis and Transplant Association Registry; <sup>5</sup>Australia and New Zealand Dialysis and Transplant Registry; <sup>6</sup>United States Renal Data System.

